



SOCIAL JUSTICE PLATFORM DATA GUIDE: INTEGRATING EQUITY INTO DATA ANALYSIS

Authors, SJP Data Sources & Analysis Team: Hannah Leker, Kirbi Joe,
Julianna Bernardi, Hannah De los Santos

Social Justice Platform Data Guide

Integrating Equity into Data Analysis

By SJP Data Sources and Analysis Team: Hannah Leker, Kirbi Joe, Julianna Bernardi, Hannah De los Santos

As data scientists and analysts, it is important that we integrate equity considerations into our work. Models, analyses, and data sets created without consideration of equity have perpetuated unequal societal structures and policy decisions. Consideration is needed at each stage of a data project to move towards a continual goal of more equitable outcomes. This data guide will provide recommendations, resources, and key questions to ask when considering equity at each project stage (note that proper methodological rigor for all analyses, statistics, and modeling should always also be considered throughout your project). Links to other helpful resources and tools are also included.

Key themes:

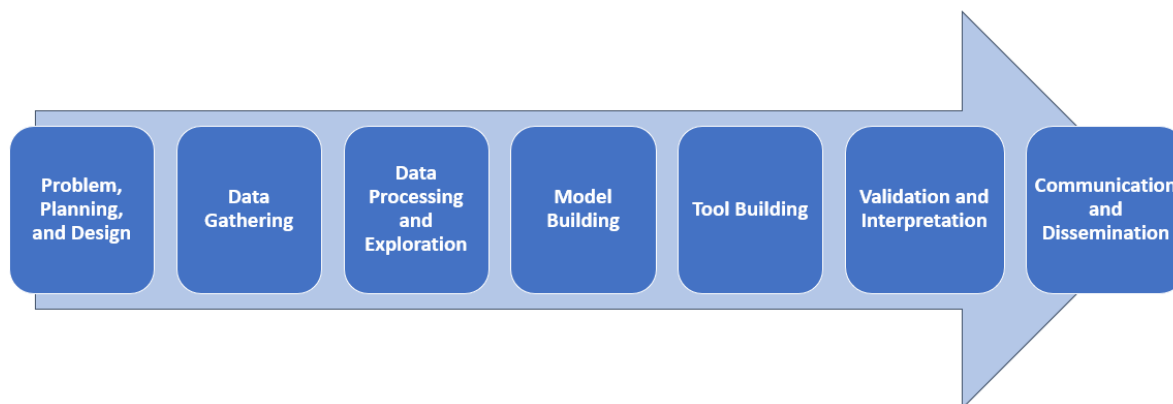
- Find ways to **engage the affected community** at multiple stages.
- **Acknowledge limitations**, and work to raise general awareness of these limitations.
- **Consider downstream impacts** of your decisions throughout the process.
- Carefully consider how to **communicate about your work with different audiences**.

Defining Equity

Equity is the effort to provide different levels of support based on an individual’s or group’s needs to achieve fairness in outcomes. Compared to equality, equity acknowledges differences in starting points and the need to correct the imbalance perpetuated by systems, policies, programs, and values ([CSSP, Key Equity Terms & Concepts](#)). Equity is not linear and must be continually re-evaluated. Equity is both reparative and forward thinking, and does not focus only on the present, but also root causes from the past as well as preventing future inequities.

Equity at every stage

In this section, you will find considerations and questions to think about at each stage of a project, informed by MITRE work and the external resources linked throughout and on the last page of this guide. Some of these steps may not be applicable for every project; this guide is intended to be modular and you can focus on the steps that are relevant to your analysis.





PROBLEM, PLANNING, AND DESIGN

DO:

- **Consider the populations you are modeling and how to integrate community partners** from underserved communities and those who this work may impact, with a focus on populations that are diverse and representative.
 - This may include activities such as listening sessions with communities, meeting with community leaders, or engaging with local organizations.
 - Plan to [add informed consent to your responsible data practices](#).
 - Plan to [engage communities as partners in research and credit them for their contributions](#).
 - [Gather community input to inform your research design](#).
 - Learn about the power dynamics between community organizations, researchers, and funders in the [Why Am I Always Being Researched](#) guidebook.
 - Consult resources to inform community outreach, such as MITRE’s Innovation Toolkits for [problem framing](#), [partner identification](#), and [partner engagement](#).
- **Consider how [your own background and bias](#) may influence your work.**
- **Work to [develop equitable research questions](#).**

ASK:

- **How are you involving community partners?**
 - [Are impacted communities involved](#) in the process of shaping the questions you seek to answer?
 - How can you ensure all interested parties, from technical experts to affected communities, are [included equally in your plan](#)?
 - How will you explore structures and perspectives [beyond your own experience](#)?
- **How will you make decisions around planning and design?**
 - How will you craft [research questions that aren’t already biased](#) in an unexamined way?
 - [Who will you prioritize](#) when selecting between different methodologies that may elevate one group or another?
 - Do your goals involve [using historical datasets in ways that are different than originally intended](#)?
- **What are the downstream effects of your analysis? Who is affected?**
 - How might your model’s predictions [change the behaviors](#) you are observing?



DATA GATHERING

DO:

- **Consider diverse data sources**, including qualitative data, and community/use-case specific data.
 - Consider [asset-framing](#) when selecting data to avoid [deficit-only framing](#).
 - When collecting primary data – consider using a [racially diverse team to collect data](#), and carefully [consider your data collection instruments](#) to reduce bias.
- **Remember that “data measures what is collected”** – consider **how** the data is being measured and how that measurement may differ for underserved communities.
 - Example: Due to [mental health stigma in many Black communities](#), individuals may be less likely to seek mental health care, leading under-reporting of cases for these communities.
 - Consider potential for bias and resulting limitations.
 - Consider how equitable sampling was for existing datasets and/or how to make sampling more equitable for data you are gathering.
- **Use stratified data** where possible and applicable.
 - If stratified data is unavailable, consider how the data may manifest differently across subgroups.
 - Remember that because [race is not included as a predictor, does not mean that it is “unbiased”](#).
- **Balance locating data on minority populations with privacy concerns.**
 - Only ask for and use personally identifiable information (PII) when necessary and consider how to [ensure confidentiality and security](#) of your data.
- **[Understand collection processes and limitations](#) of second-hand data.**
 - Consider creating a [“data biography”](#).
- Review Digital Impact’s [Four principles to guide civic society’s use of digital data](#) to understand how to manage your digital data.

ASK:

- **How, for whom, and by whom, and to what end** was the data obtained?
 - When collecting your own data, work with the researched community to [ensure that your research benefits the community](#).
- **Was permission granted to obtain data?** Would individuals be comfortable if they knew it was being obtained and how it was being used? [Affected communities should have a say in what data are collected and how data are used](#).



DATA PROCESSING AND EXPLORATION

DO:

- **Consider alignment of datasets** and make sure that subgroup definitions align.
- **Embed your perspective on equity** into the choices and assumptions made in your model. Variable processing, data processing, how variables are used, and more reflect the experience and understanding of those creating the model.
 - See Child Trends’ [Guide to incorporating a racial and ethnic equity perspective throughout the research process](#).
- **For quantitative analysis** –
 - [Tips for disaggregating data](#) – Disaggregate by subgroup when possible, but be aware of when disaggregation can obscure racial and ethnic differences within groups. Look beyond race and consider intersectionality.
- **For qualitative analysis** – [Ask explicit questions about communities’ concerns](#).



MODEL BUILDING

DO:

- **Stratify variables** where possible.
- **Be aware of biases for different models and methodologies.** Resources include:
 - [The We All Count Methodology Matrix](#)
 - [Articles, reports, and tools to learn technical approaches](#) to address race fairly in algorithms.
 - [Ethics and Empathy in Using Imputation to Disaggregate Data for Racial Equity](#) when considering methods to append race and ethnicity onto datasets.
- **Be aware of the biases of data fed into your model** (“garbage in, garbage out”). Resources include:
 - [Consider how your model could be used by an “adversary.”](#)
 - Be wary of the implied or explicit [assumption that white is the normative, standard, or default position](#).



TOOL BUILDING

DO:

- **Consider accessibility** – how the visualizations, interfaces, and other parts of your tool can be accessed.
 - Include colorblind-friendly and accessible color choices using resources like [ColorBrewer](#) and [Color Universal Design](#), and consider [508 compliance](#).
- **Learn how to [apply racial equity awareness data visualization decisions](#).**
 - Consider implications of choices including [language, data labels, ordering, colors and icons](#), visualization approaches, and more.
- **Consider your audience** and how different groups will interact with the tool. Language choice is essential!
 - The MITRE [Painstorming Innovation Toolkit](#) provides a structured method for gathering insights about users or user identities.
- Review these [10 Design Principles for Online Data Tools](#).



VALIDATION AND INTERPRETATION

DO:

- **Validation:**
 - Conduct spot checks and validate with affected communities to ensure “no modeling without the modeled”.
 - Tips for [community involvement in data interpretation](#).
 - Resource: [Data Walks: An Innovative Way to Share Data with Communities](#).
 - Use literature and qualitative feedback to verify work.
- **Interpretation:**
 - Acknowledge and understand that [determining what results mean is a subjective process](#).
 - Support your interpretation by having [a clear framework](#) showing how your analysis plan, motivation, definition of equity, and data support your conclusions.
 - [Consider context](#) when interpreting your data/model outcomes to ensure you don’t discount upstream factors.



COMMUNICATION AND DISSEMINATION

DO:

- **Consider your audience**, an [asset-framing lens](#), [language choices and messaging](#), and visualization choices when designing your community and dissemination strategies.
 - Consider using resources such as [Race Forward's Race Reporting guide](#) and the [Native American Journalists Association's resources](#) to guide reporting of information.
 - Consider the [ideal medium for disseminating findings](#) for different audiences (ex: presentations at community events, data walkthroughs, forums, etc.).
 - [Consider the study population or community as a primary audience](#) for your work.
 - Bring in affected communities to assist in drafting and verifying language choices.
- **Clearly acknowledge limitations and biases** of your work – be honest!
- **Consult resources on how to equitably communicate**, such as:
 - We All Count's [3 Steps towards Distributing Data Products Equitably](#),
 - the Annie E. Casey Foundation's guide to [Reporting Data Using a Racial Equity Lens](#), and
 - the Urban Institute's [Guide to Data Chats: Convening Community Conversations About Data](#)
- **Share your data** so that other researchers can use it, and to minimize the burden of multiple inquiries for information from the community being studied.

ASK:

- Have you communicated about your model/data/results so [that the community who contributed to your work can view and understand results](#)?
- **Have you engaged a variety of stakeholders** to ensure your work's accessibility to all groups who will use this?
- **Have you clearly communicated how equity was considered in the model** and how any [tests for bias were performed](#)?

Real World Examples:

Learn more from real world examples of how data and algorithms have been used to perpetuate racism, [such as those listed here](#). Below, we think through interventions at each step of the process for one example.

Background: In 2019, a widely used healthcare [algorithm developed by Optum was found to have a racial bias](#) that underestimated the health needs of Black patients. This algorithm was intended to help hospitals to identify high-risk patients with more health needs, allowing the hospitals to focus more resources on these high-risk patients to keep people healthier and contain costs. However, researchers later found that because this algorithm used a patient's previous healthcare costs as a measure for health need, Black patients were assigned lower health risk scores than White patients who were equally sick, and a similar score for risk of future health needs was assigned to White patients that were less sick as to Black patients with more health conditions/diseases to manage. The use of health costs as a measure for health needs does not consider racial disparities in access to and use of health care services. These racial disparities result in Black patients overall receiving fewer health care services and incurring lower health care costs (compared to equally sick White patients). The use of this algorithm to allocate resources to patients would result in Black patients with more health conditions being less likely to receive extra care than White patients that are less sick, exacerbating existing racial disparities in medicine.

Let's walk through the steps applicable to the design and implementation of this algorithm to see relevant considerations and where this racial bias can be corrected:

Problem, Planning, and Design:

- Consider the different patient populations that the model will impact, and whether the model could impact different patient populations in different ways.
- Health care cost data are not typically collected with the intent of predicting health status. Consider if using historical data for a use not originally intended will have negative unintended consequences.

Data Gathering:

- Think of ways that your predictor measure (in this case health care costs) may be biased. Are there certain population groups that tend to have lower health care costs for reasons unrelated to the outcome you are modeling (in this case health risk and need for care)?
- Consider that data may manifest differently between population groups.
- Race was not included as a predictor in this algorithm; however, it is important to acknowledge that does not mean that it is “unbiased,” or that the selected measure (cost) is race-neutral.

Data Processing and Exploration:

- Perform exploratory data analysis to examine differences in selected measures between population groups to inform and confirm variable selection. This may reveal that Black patients tend to have lower overall healthcare costs, but not lower overall incidence of health conditions.

Model Building:

- Carefully consider variable selection. Once the bias in this model was identified, a [solution was identified—to select a different measure on which to base risk scores; a prediction of future health conditions](#), rather than health care costs.

Validation and Interpretation:

- Share results of the model with a representative focus group of patients (the affected community) for validation and spot checks of the results and of your interpretation.
- Have others audit and validate your model and results—in this case [external review of the algorithm resulted in the bias being identified](#) and allowed for development of solutions.

Communication and Dissemination:

- Carefully consider how to clearly communicate the intended and appropriate uses of your data tool or algorithm. Optum asserted that “the cost model is just one of many data elements intended to be used to select patients for clinical engagement programs, including most importantly, the doctor’s expertise.” Clearly communicating any known limitations and weaknesses upfront may have prevented the algorithm from being used in unintended ways.

Links to External Resources:

GENERAL DATA EQUITY GUIDES:

- [5 Steps to Take as an Antiracist Data Scientist](#) from RTI International
- [The Data Equity Framework](#) from We All Count
- [Data Equity: Six steps beyond data disaggregation](#) from the William + Flora Hewlett Foundation
- [Data for Equity](#) from the Data Quality Campaign
- The [Data Justice Lab](#)
- [Principles for Advancing Equitable Data Practice](#) from the Urban Institute
- [A guide to incorporating a racial and ethnic equity perspective throughout the research process](#) from Child Trends
- [Five guiding principles for integrating racial and ethnic equity in research](#) from Child Trends
- [Four principles to guide civil society's use of digital data](#) from Digital Impact
- The [Why Am I Always Being Researched?](#) Guidebook from Chicago Beyond
- [Equitable Data Analysis: Lessons from a COVID-19 Research Collaborative](#) from RAND
- [Elevate Data for Equity](#) from the Urban Institute

RESOURCES BY TOPIC:

Communicating and Disseminating Information:

- [Guide to Data Chats: Convening Community Conversations About Data](#) from the Urban Institute
- [Data Walks: An Innovative Way to Share Data with Communities](#) from the Urban Institute
- [Reporting Data Using a Racial Equity Lens](#) from the Race Matters Toolkit and the Annie E. Casey Foundation
- [3 Steps towards Distributing Data Products Equitably](#) from We All Count
- [Race Reporting Guide](#) from Race Forward
- [Reporting Guides](#) from the Native American Journalists Association
- [Talk To Your Boss Sheets](#) from We All Count

Data Visualization:

- [Applying Racial Equity Awareness in Data Visualization](#) from the Urban Institute

Selecting Analytic Methods:

- [The We All Count Methodology Matrix](#) from We All Count

Data Gathering and Management:

- [An Introduction to the Data Biography](#) from We All Count
- [The We All Count Data Biography Template](#) from We All Count

Disaggregating Data:

- [Ethics and Empathy in Using Imputation to Disaggregate Data for Racial Equity](#), Landscape Scan Findings published by The Urban Institute
- [How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications](#) published in Penn State University Press

Tool Design:

- [Powering Health Equity Action with Online Data Tools: 10 Design Principles](#) from Ecotrust

Big Data Research:

- [Ten simple rules for responsible big data research](#) published in PLOS

Cross-sector Data Sharing and Integration:

- [A Toolkit for Centering Racial Equity throughout Data Integration](#) from AISP